Disability Awareness Month

LEGISLATIVE FORUM

A good way to increase public awareness about disability issues is to organize a legislative forum in your community. The forum has two purposes: 1) it educates people about disability issues by facilitating a lively discussion; and 2) it gives state and federal legislators an opportunity to discuss proposed disability legislation and listen to constituents' concerns.

Planning the Event

It will be helpful to form a small committee of active individuals who can coordinate the event and delegate tasks as appropriate. Before inviting legislators, make sure a location is available to hold the event. Free and ample parking is another consideration when choosing a location. Generally, when legislators make a local appearance, especially to discuss issues, there is a large crowd. Choose a location with a large stage area on which the legislators can sit or a podium from which they can easily be seen. There should be plenty of seating for the audience.

You should also make sure the location is accessible, including accessible parking spaces, ramps, accessible bathrooms, sign language interpreters, hearing aid technology or other disability access technology. Make sure the location is easily reached by public transportation or that transportation will be easy to arrange for persons with disabilities who need vans with lifts. The Governor's Planning Council has resource materials on how to plan an accessible meeting. For more information, call the Council at (317) 232-7770 (voice), (317) 232-7771 (TT), GPCPD@gpcpd.org (e-mail) or visit the Council's Web site at www.state.in/GPCPD.

It's important to schedule legislators weeks or even months in advance. Their availability depends on the schedule of the legislative session. If you know when legislators will be on recess, try to schedule the legislative forum during that time. Hopefully, you'll be able to have the forum in March to coincide with Disability Awareness Month. If not, it's still an excellent event to improve community awareness.

And, a well-organized legislative forum can be just as beneficial to legislators as it is to your community. You might want to get a sense of a key candidate's schedule and availability prior to scheduling the forum.

Call the offices of your local and federal representatives. If he or she is an incumbent it might be most effective to find a colleague who has a relationship with his or her office to make the call. Ask to speak directly to the candidate when you call the office to extend the invitation. If appropriate, ask for the scheduler or the public relations or public affairs staffer. You might also want to assume you will be able to get the other candidates for your forum and advise the public affairs staffer that the other candidate is being/has been contacted and is attending.

Be enthusiastic about the event when you describe the forum: Emphasize that it is an opportunity for the candidate to present his or her views on all issues, including disability-related topics. If the staffer asks for clarification on disability-related issues, say topics such as Medicaid, special education, the ADA or SSI for children with disabilities are of great interest to attendees. Remind the candidate or staffer of the number of people with disabilities and their family members and associates you expect to attend the forum. Explain that your group is organizing a legislative forum and would like the senator or representative to participate. Provide the details of the forum including the topic of discussion, time, date, place (if known) and other invited participants. You can describe the topic of discussion as local disability issues and request a progress report on new or pending disability legislation.

The legislative assistant will probably ask you to send a formal request in writing (see sample). If so, mail it right away and then follow up a few days later to make sure the letter was received. It could take some time to get a response, so the sooner you make the initial contact with the representative's office, the better. Once all the invited legislators have responded, send a confirmation letter to those who will be attending the forum (see sample). One week prior to the event, contact the legislators' offices to reconfirm.

Room Set-Up

Coordinate with the building manager or your contact about how you want the stage and audience areas set up. This includes seating, sound and lighting. If legislators

will be sitting in a panel, have a microphone for each of them. If you are using a podium, have a microphone attached to the podium. Arrange for two or three standing microphones to be placed around the room so that audience members can ask questions.

Ask someone from your group to be "Hospitality Chairperson." That person will be responsible for making name cards to place in front of each legislator, if applicable, or name tags. A pitcher of water and glasses should be available for the legislators. The Hospitality Chairperson should also greet legislators and media representatives at the event.

One week prior to the event, reconfirm the room reservation and all equipment and set-up requests.

Forum Procedure

Ask someone from your community or group who is an active disability advocate and understands local issues to serve as moderator of the forum. Several weeks before the forum, your group should meet with the moderator to determine which issues to discuss and the specific questions to ask the legislators. Once the questions are developed, mail copies to all the legislators who are attending so they can prepare.

It will be the moderator's job to keep the discussion on track. He or she will present an issue and pose a question. The moderator should also make sure each legislator gets a chance to respond. Because the discussion might lead to other issues, it's important that the moderator has a solid understanding of disability issues so he or she can ad-lib other questions. This part of the forum should last about one hour and then discussion should be opened to the audience. Have a set time for the question-and-answer session. Limit each audience member to one question and two minutes at the microphone. Try to keep the forum no longer than two hours because the legislators have other obligations.

Arrange beforehand for specific questions to be asked by members in the audience. Encourage persons with disabilities and their family members to ask questions such as the following: "Hi. I'm Jeannie Smith, parent of a nine-year-old, Greg, who has severe disabilities resulting from cerebral palsy. My question is about special education. Do you believe children with all kinds of disabilities belong in the regular classroom with their peers?" Or, "Hi. I'm Frank Green, and I benefit greatly from Medicaid right now as

it pays for personal assistance services and allows me to live a regular life. Will you support a federal requirement in Medicaid for persons with disabilities as states are given more flexibility by Washington?" Other audience questions could address negative statements such as disparaging comments about the ADA. An audience member could read a quote back to the candidate and ask them to explain what they meant and if they are going to change their mind as they learn more about disability issues.

Publicity and Invitations

Plan on overflowing the forum site. Invite as many persons with disabilities, family members and associates as possible. Make attractive posters or notices and circulate these materials widely in the disability community. You might want to send out personalized notices with an RSVP to let you know how many persons will attend, including companions. Follow up with phone calls and reminders.

Media Relations

About three weeks before the event, send a calendar release to local newspaper editors and a public service announcement to radio public service directors (see samples). Call a few days later to make sure the release or PSA was received and ask for the newspaper or station's help in publicizing the event.

One week before the event, fax a media advisory to all print and broadcast media outlets. For print publications, send the advisory to either government reporters, disability reporters, city editors or photo editors. For broadcast outlets, send the advisory to government reporters or news directors. Again, follow up by phone and try to get a confirmation from each media outlet.

At the forum, be sure to take black-and-white photos to mail to newspapers that didn't send a photographer but do accept photos. Also prepare a release about the forum (see sample) that describes the issues and legislation that were discussed. Mail the release to any media outlet that didn't send a reporter.

After the event, mail thank you notes to all media outlets that provided coverage before or after the event (see sample). Let the reporter or editor know that the (Anytown) Planning Council for People with Disabilities appreciated the coverage of the forum because it will help educate people about disability issues in (Anytown).

Another way to promote the event is to send notices to community groups and ask them to announce the forum at their meetings.

The Day of the Event

Arrive at the site about an hour early to make sure the room is properly arranged. Check the seating, sound system and lighting, if necessary, of both the stage and audience areas. Also check the accessibility of the room for wheelchair users. The Hospitality Chairperson should have the name cards and water pitchers and be ready to meet and greet legislators and media representatives.

Have an information table by the door staffed with a representative from your organization. The person can answer questions, distribute materials about your group or Awareness Month and serve as a check-in point for legislators and the media. The staff member should remain there throughout the forum in case some media representatives arrive late.

The moderator will give a brief introduction about Disability Awareness Month, your organization and the format of the forum. Then he or she can introduce the legislators and begin with the first issue and round of questions. It is the moderator's duty to keep track of time. Remember, try to keep the forum at or under two hours.

Assign someone to take black-and-white pictures. The pictures should be of good quality because you're sending them to newspapers.

During the audience question-and-answer session, you and the Hospitality Chairperson can select audience members who have questions. Have one person at each microphone at all times and have the moderator call on audience members in a continuous order. This will keep the questions moving at a steady pace. Each audience member should only ask one question at a time.

After the question-and-answer session, the moderator should end the forum by thanking the legislators and reminding the audience to celebrate Disability Awareness Month. If your group has other events planned, the moderator can discuss those as well.

Make sure you announce that voter registration forms are available for all participants who are not currently registered to vote or who need to update their voter registration.

After the Event

Mail a news release and photo(s) to any print publications that did not attend. Identify everyone in the photo(s) by typing their names on an adhesive label and attaching it to the back of each photo.

The final step is to thank everyone who was involved in the forum. Send thank you letters to the legislative representatives, media representatives, building manager and anyone else who volunteered their time or resources (see sample).

Sometimes a reporter with the best intentions inadvertently uses language in a story that creates negative impressions of people with disabilities. Examples include "the handicapped" or "the disabled person." If you receive such media coverage, send a thank you letter, but also include suggestions and a set of guidelines for correct language when referring to people with disabilities. A sample letter is enclosed, along with "Guidelines for Reporting and Writing about People with Disabilities," produced by the Indiana Governor's Planning Council for People with Disabilities.

Note: For more information about lobbying or contacting your legislators, the Governor's Planning Council offers a brochure entitled *The Legislative Process*. To order a brochure free of charge, please call the Council at (317) 232-7770 (voice), (317) 232-7771 (TT), GPCPD@gpcpd.org (e-mail); or visit the Council's Web site at www.state.in.us/GPCPD.

(Sample Invite Letter for Legislators)

(Date)

Representative (Joe Smith) c/o (Ann Jones), legislative assistant Indiana General Assembly (Address) (City, State Zip)

Dear Representative (Smith):

To celebrate Disability Awareness Month, the (Anytown Planning Council for People with Disabilities) is holding a legislative forum to discuss disability issues. We invite you to be part of our legislative panel to discuss the progress of disability legislation and listen to the concerns of constituents with and without disabilities.

The forum will take place (Tuesday, March 3, at 7 p.m.) in the (Anytown High School auditorium). Our group will provide you with a list of issues and questions to be discussed. There will also be an audience question-and-answer session. The forum should last no longer than two hours.

We hope that this forum will serve as an educational tool for you and the people of our community and will demonstrate that people with disabilities are vital, contributing members of the community. Our goal is to raise awareness of disability issues and disability-related legislation.

We appreciate your support of people with disabilities and hope to see you at the forum. I'll be contacting your legislative assistant, (Ann Jones), to confirm your attendance.

Sincerely,

(John Doe) (President) (Anytown Planning Council for People with Disabilities) (Sample Confirmation Letter for Legislators)

(Date)

Representative (Joe Smith) c/o (Ann Jones), legislative assistant Indiana General Assembly (Address) (City, State Zip)

Dear Representative (Smith):

The (Anytown Planning Council for People with Disabilities) is pleased that you will be participating in our Disability Awareness Month Legislative Forum.

The forum will take place (Tuesday, March 3, at 7 p.m.) at the (Anytown High School auditorium). Please plan on arriving at the school about 15 minutes early. The forum should last no longer than two hours.

Enclosed are disability issues that will be addressed at the forum as well as a list of questions. We would also like for you to give the audience an update on recent or pending disability legislation.

Please call me at (123-4567) if you have any questions. I look forward to seeing you in March.

Sincerely,

(John Doe) (President) (Anytown Planning Council for People with Disabilities)

Enclosure

(Sample Calendar Release)

For Immediate Release (Date)

Contact: (Your Name) (Your Phone)

CALENDAR RELEASE

The (Anytown Planning Council for People with Disabilities) is holding a Legislative Forum in celebration of Disability Awareness Month at (7 p.m., Tuesday, March 3) at the (Anytown High School auditorium). (List participating legislators) will discuss local and national disability issues and recent or pending legislation. There will be an open question-and-answer session at the end. The forum is open to the public, and admission is free. For more information, contact (John Doe) at (123-4567).

(Sample Radio PSA)

 (Your Name)
 Start: (February ___, 20--)

 (Your Phone)
 Stop: (March ___, 20--)

TIME: 15 seconds

"LEGISLATIVE FORUM"

ANNOUNCER

TO CELEBRATE DISABILITY AWARENESS MONTH, THE (ANYTOWN PLANNING COUNCIL FOR PEOPLE WITH DISABILITIES) IS HOLDING A LEGISLATIVE FORUM, (TUESDAY, MARCH 3, AT 7 P.M.) AT THE ANYTOWN HIGH SCHOOL AUDITORIUM). STATE AND FEDERAL LEGISLATORS WILL DISCUSS DISABILITY ISSUES AND RELATED LEGISLATION AND ANSWER AUDIENCE QUESTIONS. THE EVENT IS FREE AND OPEN TO THE PUBLIC.

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(Sample Media Advisory)

For Immediate Release (Date)

Contact: (Your Name) (Your Phone)

MEDIA ADVISORY

What Disability Awareness Month Legislative Forum

State and federal legislative representatives will discuss disability issues on the local and national levels and report on recent or pending legislation. Audience members will be able to ask

questions at the end of the program.

Who (List participating legislators and titles)

When (Tuesday, March 3)

(7 - 9 p.m.)

Where (Anytown High School auditorium)

Why March is Disability Awareness Month. The (Anytown Planning

Council for People with Disabilities) is sponsoring the forum to

increase public understanding about disability issues.

Note The forum is open to the public. Admission is free.

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(Sample News Release)

For Immediate Release (Date)

Contact: (Your Name) (Your Phone)

Legislators Discuss Disability Issues at Public Forum

(Anytown), Ind. — (List legislators and titles) attended a legislative forum held by the (Anytown Planning Council for People with Disabilities) last night at (Anytown High School). Local and federal disability issues were discussed as well as recent and pending disability legislation such as (specify legislation).

"The legislative forum was a good way to raise awareness about the abilities of people with disabilities as well as the disability issues facing our community," said (John Doe), (president of the Anytown Planning Council for People with Disabilities), which sponsored the event.

Representative (Joe Smith) reported on disability legislation in the Indiana General Assembly. (Give details....)

The legislators answered questions posed by Moderator (Sue Johnson), (title), for about (one hour) followed by questions from the audience. About (____) people attended the forum, which was one of several Disability Awareness Month activities planned throughout the month.

(Sample Thank You Letter for Legislators)

(Date)

Representative (Joe Smith) c/o (Ann Jones) Indiana General Assembly (Address) (City, State Zip)

Dear Representative (Smith):

On behalf of the (Anytown Planning Council for People with Disabilities), thank you for participating in the Disability Awareness Month Legislative Forum.

The forum provided our residents with important information about disability issues and increased awareness and understanding. We also hope you gained some insight about concerns facing our community. We're pleased to have legislators such as you who are truly interested in listening to the concerns of people with disabilities, their families and friends.

Sincerely,

(John Doe) (President) (Anytown Planning Council for People with Disabilities)

(Sample Thank You Letter for Media)

(Date)

(Ms. Jane Doe) (City Editor) (The Anytown Courier) (Address) (City, State Zip)

Dear (Ms. Doe):

On behalf of the (Anytown Planning Council for People with Disabilities), thank you for providing pre- and post-event coverage of the Disability Awareness Month Legislative Forum.

The forum provided (Anytown) residents with important information about disability issues as well as an opportunity to express their concerns with legislators. We hope our community will continue to study the issues and work toward improving opportunities for people with disabilities.

We appreciate your interest in increasing disability awareness.

Sincerely,

(John Doe) (President) (Anytown Planning Council for People with Disabilities) (Sample Thank You Letter – With Suggestions for Appropriate Language)

(Date)

(Mr. John Doe) (Title) (XYZ Media) (123 Main Street) (Anytown, Indiana 46000)

Dear (Mr. Doe):

Thank you for your recent article/broadcast about our organization/event. Although we always appreciate coverage about people with disabilities and the issues that concern them, it is also important to realize that the way a reporter tells a story can make a significant difference in how people with disabilities are perceived in the community.

Reporting on the disability community is just like reporting on any other minority group; there are "correct" words and phrases to use. The Indiana Governor's Planning Council for People with Disabilities and other disability organizations emphasize "people first" language that focuses on the person first, with the disability as secondary. For example, woman who is deaf is preferred over deaf woman. In addition, people with disabilities is preferred over the handicapped or the disabled.

I have enclosed "Guidelines for Reporting and Writing about People with Disabilities." The guidelines explain preferred terminology when reporting about people with disabilities and reflect the input of more than 100 national disability organizations.

If you ever have a question these guidelines don't address, please feel free to contact me. Again, we appreciate your coverage of our organization and people with disabilities in general.

Sincerely,

(Your Name) (Title)

enclosure

Guidelines for Reporting and Writing About People with Disabilities

When writing, it's important to be concise, particularly in journalism. However, sometimes the effort to limit wordiness leads to inappropriate references to people with disabilities. The following guidelines explain preferred terminology and reflect input from more than 100 national disability organizations. These guidelines have been reviewed and endorsed by media and disability experts throughout the country. Although opinions may differ on some terms, the guidelines represent the current consensus among disability organizations. Portions of the guidelines have been adopted into the "Associated Press Stylebook," a basic reference for professional journalists.

DO NOT FOCUS ON DISABILITY unless it is crucial to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments or severe injury. Focus instead on issues that affect the quality of life for those individuals, such as accessible transportation, housing, affordable health care, employment opportunities and discrimination.

PUT PEOPLE FIRST, not their disability. Say "woman with arthritis," "children who are deaf" or "people with disabilities." This puts the focus on the individual, not the particular functional limitation. Despite editorial pressures to be succinct, it is never acceptable to use "crippled," "deformed," "suffers from," "victim of," "the retarded," "the deaf and dumb," etc.

DO NOT SENSATIONALIZE A DISABILITY by writing "afflicted with," "crippled with," "suffers from," "victim of" and so on. Instead, write "person who has multiple sclerosis" or "man who had polio."

DO NOT USE GENERIC LABELS for disability groups, such as "the retarded" or "the deaf." Emphasize people, not labels. Say "people with mental retardation" or "people who are deaf."

EMPHASIZE ABILITIES, not limitations. For example:

- Correct: "uses a wheelchair/braces" or "walks with crutches"
- Incorrect: "confined to a wheelchair," "wheelchair-bound" or "crippled" Similarly, do not use emotional descriptors such as "unfortunate," "pitiful" and similar phrases.

Disability groups also strongly object to using euphemisms to describe disabilities. Terms such as "handi-capable," "mentally different," "physically inconvenienced" and "physically challenged" are considered condescending. They reinforce the idea that disabilities cannot be dealt with directly and candidly.

SHOW PEOPLE WITH DISABILITIES AS ACTIVE participants in society. Portraying persons with disabilities interacting with people without disabilities in social and work environments helps break down barriers and open lines of communications.

DO NOT PORTRAY SUCCESSFUL PEOPLE WITH DISABILITIES AS SUPERHUMAN. Many people with disabilities do not want to be "hero-ized." Like many people without disabilities, they wish to be fully included in our communities and do not want to be judged based on unreasonable expectations.

DO NOT IMPLY DISEASE when discussing disabilities that result from a prior disease episode. People who had polio and experienced after-effects have a post-polio disability. They are not currently experiencing the disease. Do not imply disease with people whose disability has resulted from anatomical or physiological damage (e.g., person with spina bifida or cerebral palsy). Reference to the disease associated with a disability is acceptable only with chronic diseases, such as arthritis, Parkinson's disease or multiple sclerosis. People with disabilities should never be referred to as "patients" or "cases" unless their relationship with their doctor is under discussion.

LISTED BELOW ARE PREFERRED WORDS THAT REFLECT A POSITIVE ATTITUDE IN PORTRAYING DISABILITIES:

- *Brain injury*. Describes a condition where there is long-term or temporary disruption in brain function resulting from injury to the brain. Difficulties with cognitive, physical, emotional or social functioning may occur. Use "person with a brain injury," "woman who has sustained brain injury" or "boy with an acquired brain injury."
- *Cleft lip*. Describes a specific congenital disability involving lip and gum. The term "hare lip" is anatomically incorrect and stigmatizing. Use "person who has a cleft lip" or "a cleft palate."
- Deaf. Deafness refers to a profound degree of hearing loss that prevents understanding speech though the ear. "Hearing impaired" and "hearing loss" are generic terms used by some individuals to indicate any degree of hearing loss from mild to profound. These terms include people who are hard of hearing and deaf. However, some individuals completely disfavor the term "hearing impaired." Others prefer to use "deaf" or "hard of hearing." "Hard of hearing" refers to a mild to moderate hearing loss that may or may not be corrected with amplification. Use "woman who is deaf," "boy who is hard of hearing," "individuals with hearing losses" and "people who are deaf or hard of hearing."
- *Disability*. General term used for a functional limitation that interferes with a person's ability to, for example, walk, lift, hear or learn. It may refer to a physical, sensory or mental condition. Use as a descriptive noun or adjective, such as "person living with AIDS," "woman who is blind" or "man with a disability." "Impairment" refers to loss or abnormality of an organ or body mechanism, which may result in a disability.
- *Disfigurement*. Refers to physical changes caused by burn, trauma, disease or congenital problems.

- *Down syndrome*. Describes a chromosome disorder that usually causes a delay in physical, intellectual and language development. Usually results in mental retardation. "Mongol" or "mongoloid" are unacceptable.
- Handicap. Not a synonym for disability. Describes a condition or barrier imposed by society, the environment or by one's self. Some individuals prefer "inaccessible" or "not accessible" to describe social and environmental barriers. "Handicap" can be used when citing laws and situations, but should not be used to describe a disability. Do not refer to people with disabilities as "the handicapped" or "handicapped people." Say "the building is not accessible for a wheelchair-user." "The stairs are a handicap for her."
- *HIV/AIDS*. Acquired immunodeficiency syndrome is an infectious disease resulting in the loss of the body's immune system to ward off infections. The disease is caused by the human immunodeficiency virus (HIV). A positive test for HIV can occur without symptoms of the illnesses, which usually develop up to 10 years later, including tuberculosis, recurring pneumonia, cancer, recurrent vaginal yeast infections, intestinal ailments, chronic weakness and fever and profound weight loss. Preferred: "people living with HIV," "people with AIDS" or "living with AIDS."
- *Mental disability*. The Federal Rehabilitation Act (Section 504) lists four categories under mental disability: "psychiatric disability," "retardation," "learning disability" or "cognitive impairment" is acceptable.
- *Nondisabled*. Appropriate term for people without disabilities. "Normal," "ablebodied," "healthy" or "whole" are inappropriate.
- Seizure. Describes an involuntary muscular contraction, a brief impairment or loss of consciousness, etc., resulting from a neurological condition such as epilepsy or from an acquired brain injury. Rather than "epileptic," say "girl with epilepsy" or "boy with a seizure disorder." The term "convulsion" should be used only for seizures involving contraction of the entire body.
- *Spastic*. Describes a muscle with sudden abnormal and involuntary spasm. Not appropriate for describing someone with cerebral palsy or a neurological disorder. Muscles, not people, are spastic.
- *Stroke*. Caused by interruption of blood to brain. Hemiplegia (paralysis on one side) may result. "Stroke survivor" is preferred over "stroke victim."

The Indiana Governor's Planning Council for People with Disabilities would like to acknowledge the Research and Training Center on Independent Living at the University of Kansas for the usage rights of the "Guidelines."

LEGISLATIVE FORUM TIMELINE CHECKLIST

** This timeline checklist should be adjusted according to your specific planning timeframe.

| Three mont | ths before the forum: |
|------------|---|
| | Check the availability of locations suitable for the forum. |
| | Based on location availability, select a date for the forum. |
| | Contact your legislators' offices and invite them to participate in the forum. |
| | Mail a written request to legislators after the initial phone call. |
| Two month | as before the forum: |
| | Confirm legislators' participation. |
| | Confer with the building manager about the room arrangement, sound, lighting and accessibility. |
| | Appoint a Hospitality Chairperson and assign him or her duties. |
| | Assign duties to other members of your organization. |
| | Send notices to other community organizations. |
| One month | before the forum: |
| | Ask a community representative who is an active disability advocate to serve as moderator of the forum. |
| Three week | as before the forum: |
| | Mail the calendar release to newspaper editors and the PSA to radio public service directors. |
| Two weeks | before the event: |
| | Meet with volunteers to discuss last-minute details and their duties the day of the event. |

| One week before the event: | |
|----------------------------|---|
| | Reconfirm with legislators. |
| | Reconfirm location reservation, equipment needs and room arrangement with building manager. |
| | Mail the media advisory. |
| After the e | event: |
| | Send a follow-up news release to media that did not attend your event. Also send a black and white photo to newspapers that did not attend. Be sure to clearly identify those photographed. |
| | Send thank you letters to legislators, building managers and media who attended. |